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Biological and non-biological parents' experiences raising children with FASD.

by

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Abstract

Research evaluating the experiences of birth and adoptive parents raising children with a fetal alcohol spectrum disorder (FASD) is needed to ascertain facilitating factors and barriers to successful family functioning. The present study is a qualitative, descriptive investigation of raising children with FASD. Biological and non-biological parents shared their insights and experiences in unstructured interviews. This important research will help inform biological and non-biological parents, caregivers, practitioners, and government about family risk factors that may be present in the homes of children with FASD in Canada.

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Chapter I

Introduction

Recently, I had the opportunity to cut the umbilical cord when my wife gave birth to our second child. I accepted the offer, though I was much less interested in cutting the cord than I was in meeting my new son. The cord was clamped in several places, and after cutting it a small portion remained connected to my baby boy. This added to the challenge of changing the diaper of my already spastic newborn. A few days after birth, the cord blackens as it rots, and falls off. Its appearance is not much better than when it was freshly cut.

Despite its grisly appearance, this rope-like tissue played a crucial role in my son's prenatal development. The cord was my son's lifeline to his mother, channelling in oxygen and nutrient rich blood. Without it, he would have been isolated from those essential needs. The umbilical cord, however, is a channelling device and not a filter. It does not discriminate amongst the substances that pass through it. That discretionary power is left to the mother.

A teratogen is a substance that when taken by a pregnant woman harms or thwarts fetal development leading to birth defects. Such substances are not limited to illegal drugs such as cocaine. Thalidomide, presently used in some cancer treatment, was prescribed to pregnant women in the 1950s and 1960s to combat morning sickness. Thousands of children were born with severe physical malformations due to its teratogenic effects.

Due to its worldwide availability and consumption, alcohol is the most prominent of all known teratogens. "FAS represents the largest environmental cause

of behavioral teratogenesis yet discovered and, perhaps, the largest single environmental cause that will ever be discovered." (Riley & Vorhees, 1986, p. 13) Present prevalence rates of FASD suggest it is already a significant worldwide problem. However, the lack of diagnoses and the universal availability of alcohol suggest that it may actually be a much more significant worldwide concern than it already is.

I developed a strong interest in Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Spectrum Disorders (FASD) through my experiences as a Behavioural Consultant, exploring strategies and resources with families who have children with disabilities. I met with many parents of children with various disabilities, with some children exhibiting violent and even frightening behaviors. In light of perceived dangers in the homes of some parents, I wondered why I sensed feelings of hopelessness that seemed unique to parents of children with FASD. The consultation meetings with parents of children with FASD rarely ended with any helpful recommendations and left a lot of unanswered questions for parents and for me.

Although they may still feel confused by their children's deficits, parents of children with FASD have much wisdom to offer in terms of living with the effects of their children's disorders. Many of their stories are not only unique and inspiring, but can assist clinicians, teachers, and other practitioners to work empathetically with these families. Since each child with FASD presents differently, it makes little sense to provide recommendations without first consulting with parents about their individual needs. My consultations with parents, highly based on principles of

behaviourism, were not helpful. Part of the impetus for the research in this paper was to find out what parents of children with FASD experience and need.

Children with FASD can, but do not always, exhibit adaptive, academic, and social learning challenges. For those with FAS, the most severe form of the disorder, these deficits are usually apparent, and supports are more often provided. But for many children on the fetal alcohol spectrum, interventions and supports are denied because their disabilities are not visible. In this way, many children with a lighter form of FASD fall through the cracks. Paradoxically, as seen in this study, some parents wish their children were more disabled so that they could access supports they need.

The disabilities associated with FASD can be difficult to comprehend. Although some children can demonstrate extraordinary abilities in music and art among other areas, their day-to-day functioning can be deficient. David, for example, demonstrates his skill in poetry as describes life with FASD:

> Dawn has come with only half the sun
> in view for me for all my life.
> Close my eyes and open again
> reveals again only half the sun.
> During the day with only half the sun
> I can only see half as well
> stumbling, tripping throughout the day
> all because I only see half the sun.
> I strain to see more than half the sun
> because I'm told I must see more
> during my life as a half blind child.
> I've failed because of a half-seen sun.
> I struggle on against the half-seen sun.
> Pushing my life hand as I can
> knowing that I'm blind for the rest of my life.
> b/c I can only see half the sun.
> It's noon right now, with my half-seen sun,
> and I've accepted my life as it is.

I'm as normal as all the rest
even with my big old ruby half-seen sun.
Acceptance is the key to success for me.

Despite his poetic ability, David ponders in a letter, "Why do I feel normal but I still can't make a box of macaroni, do the groceries, or know when to launder my clothes?" (Badry & Lawryk, 2000)

Even when difficult behaviours are exhibited, FASD is more of a learning disorder than a behavioural disorder. Despite often having good expressive language skills, people with FASD have difficulty processing and understanding social situations. Although they may give into impulses and act without thinking, they can also knowingly engage in rule-breaking and violate social norms, while not knowing that these behaviours are "wrong", and not learning from resulting consequences. That is why my recommendations, based on behavioural principles, were not useful to parents. Difficult behaviours were frequently perceived as defiance, and opportunities to teach behaviour using consequences became items of contention. Strong expressive language becomes more of a burden than a blessing for these children, as adults and peers perceive that they ought to know better and set unrealistic expectations for them.

The dyadic relationships between the birth mothers and their children, birth mothers and birth fathers, and sometimes birth mothers and adoptive/foster parents are unique. The impacts of prenatal alcohol exposure can be difficult to cope with. Unlike other disorders such as ADHD and autism where the cause is thought to be highly genetic (and thus out of our control), the cause of FASD is attributable to the birth mother's choice to drink alcohol. Because it is within the birth mother's control

to not drink alcohol, many people, including some parents in this study, resent birth mothers for causing these children's afflictions, some calling for legal action (Armstrong, 2003). Children may also bear grudges toward their birth mothers. In a letter to his mother (Badry & Lawryk, 2000), thirteen year-old Christopher said:

> I am mad at you about everything. You don't call, or write. I'm mad at you for drinking when I was in your tummy. I know you're trying to quit, so call a doctor...If you stop drinking we could be friends.
> Good luck and best wishes.
> Chris.

Alcoholism during pregnancy, however, is a greater social and psychological problem than just making a decision whether to drink. In a letter to her son (Badry & Lawryk, 2000), one birth mother explained:

> Alcoholism is a cunning, powerful and baffling disease. I knew that drinking during pregnancy was wrong, but I could not stop. The guilt and shame I felt was intense, but those feelings only led me to drink more in an attempt to escape them...As I am typing this letter the tears are flowing. I have done this to you and I can't fix it...Son, I am deeply sorry for what I have done.

The impact of FASD on families needs to be understood more fully. This paper begins with a review of the history, diagnosis, and prevalence of FAS and FASD. The behavioural phenotype, and the etiology underpinning that phenotype, is also included. Research on parenting children with the unique challenges associated with FASD is reviewed. In the results section, parents share powerful experiences and insights into raising children with FASD, which are organized into themes for the reader. In the discussion section, themes are related to existing literature on parenting children with FASD, and recommendations are provided for empathetic practice.

Chapter II

History, Context, Literature, and Definitions

History

The deleterious effects of pre-natal alcohol exposure have been suspected for centuries. In the Old Testament it is recorded that an angel spoke to the wife of Manoah and said, "Thou shalt conceive, and bear a son. Now therefore, beware, I pray thee, and drink not wine nor strong drink" (The Holy Bible, KJV; Judges 13:3-4). In early Carthage there were laws that forbade couples from drinking on their wedding night to avoid conception under the influence of alcohol (Calhoun & Warren, 2007). In England in 1726, the College of Physicians called gin "a cause of weak, feeble, and distempered children", and in 1834 a committee on drunkenness reported to the House of Commons that children born to alcoholic mothers had a "starved, shrivelled, and imperfect look" (quoted in Warner & Rosett, 1975, p. 1400). In the late-nineteenth and early-twentieth century, an interest in studying the effects of alcohol on human development emerged in scientific literature in Europe and North America. This trend led to further research regarding still births, infant mortality, and "imbecility" in children of alcoholic parents. Later, experimental studies of the effects of prenatal alcohol exposure in animals emerged (Warner & Rosett).

A clinical description of the deleterious effects of fetal alcohol ingestion was first published by Lemoine et al. (1968). In their study of 127 children born to alcoholic parents (predominantly alcoholic mothers), these researchers noted that children presented with particular facial features, considerable growth delay,

malformations, and psycho-motor delay. The children, referred to as "the Lemoine kids" (Lemoine, 2003), demonstrated unique facial features including low arched forehead, flattened nasal base, short upturned nose, convex profile on upper lip, narrow forehead, enlarged mouth, and cupped ears. Most were born prematurely, birth weight was below the mean in every case, and children's physical growth throughout development was for the most part below average. About one-fifth of the Lemoine kids (25) presented with physical anomalies, including ocular, limb, cardiac, or visceral malformations, or cleft palate. Remarkably, Lemoine et al. also noted that these children showed cerebral immaturity based on EEG. These children were late at acquiring early motoric developmental milestones, such as sitting and walking, and language development was also delayed. Behavioural problems commensurate with hyperactivity, aggression, and inattention were observed, "They are full of life, agitated, turbulent and quarrelsome, but unstable and incapable to persist with a task" (p. 134). Lemoine et al. also noted intellectual delays, with IQs around 70. These children demonstrated "constant delays in school in all cases", and the researchers postulated that the children were "incapable of sustained studying and attaining a higher professional level" (p. 134). Although the Lemoine et al. article was "incredible in its scope and in its amazing clinical details" (Koren & Navioz, 2003), Lemoine recently noted that most of his colleagues in France did not take his study seriously (2003).

Five years later, Jones et al., a research team in Seattle, WA, provided a similar clinical description of this disorder. In their study of eight children of alcoholic mothers, these researchers noted pre- and post-natal growth deficiencies,

characteristic facial features, and limb and cardiac anomalies. Jones et al. also noted intellectual, social, and motor deficiencies (1973). In another publication later that year, Jones and Smith called this disorder fetal alcohol syndrome (1973). Jones and Smith also reported on a necropsy performed on a patient from their first study. They found disorganization of neuronal and glial cells, incomplete development of the brain, and the absence of a corpus callosum. In 1974, Jones et al. used retrospective data to explore characteristics of children born to alcoholic mothers. Forty-four percent of these children demonstrated borderline to moderate intellectual deficiency, while 32% had sufficient abnormal physical features to suggest fetal alcohol syndrome (FAS). These three studies laid the foundation for the diagnosis of FAS (Calhoun & Warren, 2007). Although Jones et al. (1973) are often credited with the first clinical description of fetal alcohol syndrome, clearly this is not the case (Koren & Navioz, 2003). Lemoine (2003) commended the Seattle research team for bringing the effects of prenatal alcohol exposure to the forefront:

> Fortunately in 1973, Smith in Seattle, after reading the abstract on my work in the French Pediatric Archives, published 8 cases with the same conclusions…This is an amusing fact: the 127 cases of a modest paediatrician from Brittany (France) did not create any interest, whereas 8 American cases became immediately convincing and the syndrome became rapidly known in France and in the whole world. Thanks go to Smith for being able to impose the existence of this reality and its dramatic consequences. (p. e2)

Although the first and second publications by Jones et al. (1973; Jones & Smith, 1973) were case studies of only 11 children in total, the findings initiated tremendous impetus in fetal alcohol research. Shortly after the aforementioned articles were published, numerous reports identifying patients with FAS emerged (Calhoun & Warren, 2007).

Soon after interest in studying the phenomenon of fetal alcohol gained momentum, researchers recognized that they were encountering alcohol-affected children, some of whom were not demonstrating each of the diagnostic signs of FAS, namely growth deficiency, mental deficit, and facial dysmorphology. To address this apparent difference, the term "suspected fetal alcohol effects" (FAE) was introduced (Clarren & Smith, 1978). This term was intended to identify anomalies compatible with prenatal alcohol exposure in the absence of a diagnosis of FAS. However, FAE was often applied inappropriately to children with minor growth or behaviour problems based on the suspicion of prenatal alcohol exposure without differential diagnosis (Aase, Jones, & Clarren, 1995). Nevertheless, the concept of FAE introduced the possibility of a spectrum of disorders associated with prenatal alcohol exposure.

A new classification of fetal alcohol spectrum disorders (FASD) was later recommended by the Institute of Medicine in 1996. This term includes: FAS with and without confirmed maternal alcohol exposure; partial FAS; alcohol-related birth defects (ARBD); and alcohol-related neurodevelopmental disorder (ARND) (Calhoun & Warren, 2007). FASD is used as an umbrella term identifying deficits related to all degrees of prenatal alcohol exposure. However, FASD is intended as a descriptive

term and not for use as a diagnosis (Chudley et al., 2005). Having this overarching term is helpful for families, clinicians, and researchers to understand and describe better the effects of prenatal alcohol exposure on fetuses (Sokol, Delaney-Black, & Nordstrom, 2003).

Diagnosis

The diagnostic criteria for FAS have been relatively stable since the disorder was first described by Jones et al. in 1973 (Astley & Clarren, 2000). FAS was characterized by growth deficiency, central nervous system dysfunction, characteristic facial abnormalities, and exposure to alcohol prenatally. However, problems with diagnosis arose when individuals did not meet all diagnostic criteria for FAS but were still impacted by the effects of prenatal alcohol exposure (Clarren & Smith, 1978). Diagnostic guidelines for FAE, ARBD, and ARND were available (Sokol & Clarren, 1989), but the criteria were unspecific, unclear, and lacked objectivity. In addition, these terms were poorly defined and failed to represent the diversity of disability present (Astley & Clarren, 2000).

To assure more accurate diagnoses of prenatal alcohol exposure, Astley & Clarren created the 4-Digit Diagnostic Code (2000). The four-digit code uses quantitative, objective Likert scales that measure diagnostic features of FAS in the following order; growth deficiency, FAS facial characteristics, central nervous system dysfunction, and risk of prenatal alcohol exposure. Each digit of the four-digit code represents the expression of each of the above diagnostic categories, with 1 representing absence of the feature and 4 representing a strong presence of the feature. For example, a patient presenting with no growth deficiency (code 1), mild

facial phenotype (code 2), probable brain damage (code 3), and high risk of prenatal alcohol (code 4), would be given a 4-digit code of 1234.

A particular strength of Astley & Clarren's (2000) 4-digit code is that individual Likert digits in each category are obtained objectively. For example, the growth deficiency digit is derived from percentile rankings of the patient's height and weight. If the patient is below the 3rd percentile in both height and weight, they will be given a code 4. If the patient is below the 3rd percentile for height but above the 10th percentile for weight, they will be given a code 2. Similar objective ranking procedures are provided for all diagnostic categories, providing a more reliable diagnostic procedure than the traditional gestalt method.

Once a 4-digit code is assigned a diagnostic category can be determined. All possible codes are collapsed into one of 22 diagnostic categories labelled A through V. Names of the categories are created sequentially from four terms: "sentinel physical finding", "neurobehavioural disorder", "static encephalopathy", and "alcohol exposure status" (Astley & Clarren, 2000). The first two categories (A and B) meet the diagnostic criteria for FAS, the third (C) is Atypical FAS, and the fourth (D) is FAS Phenocopy. The rest of the categories (E-V) do not meet the criteria for FAS, but still provide a clinical description of the patient. In this way, clinical FAS features of the patient are described even in the absence of a diagnosis, which is another strength of the 4-digit code.

Other diagnostic procedures emphasize a multidisciplinary approach. In their guidelines for diagnosis for Canada, Chudley et al. (2005) consulted with 100 Canadian and American experts in the diagnosis of FAS. These experts come from

varied professional backgrounds, societies, and levels of government. Chúdley et al. propose six guidelines to a comprehensive diagnostic assessment, including: screening/referral; detailed physical examination and differential diagnosis; neurobehavioural assessment; treatment and follow-up; history of maternal alcohol consumption during pregnancy; and diagnostic criteria for FAS, partial FAS, and ARND. The authors note that because of the range of disability associated with prenatal alcohol exposure, the multidisciplinary approach is essential for accurate diagnosis and treatment.

Diagnosis of the effects of prenatal alcohol exposure has progressed remarkably since the first diagnostic criteria for FAS were advanced by Jones et al. (1973). Although the reliability of diagnosis has advanced significantly, evaluating the validity of diagnostic criteria needs to be a higher priority (Calhoun & Warren, 2007). Developing a behavioural phenotype of FASD has been difficult because of the large range of possible deficits associated with the disorder. There is presently no specific biological test of FASD (Chudley, et al., 2007), though biomarkers are being explored (Chudley et al., 2005). In addition, the diagnosis of adults with FASD poses unique challenges because there may be a catch-up of functioning, and physical features can change over time (Chudley et al., 2005). Continued advances in valid diagnoses of FASD should lead to more appropriate patient care, prevention of secondary disabilities, more accurate prevalence rates, and further prevention of FASD (Astley & Clarren, 2000).

Prevalence

Epidemiological studies in the United States indicate prevalence rates for FAS in the 1980s and 1990s to average 0.5-2/1,000 births (May & Gossage, 2001). Studies for prevalence FASD are sparse due to the recency of the term, but some researchers estimate that 9/1,000 births are impacted by prenatal alcohol exposure (Sampson et al., 1997). Unfortunately, there have been no epidemiological studies of FASD across Canada to date (Chudley et al., 2005), but there have been several community-based studies of prevalence. A recent study of an aboriginal community in Atlantic Canada found high incidence rates for FASD, at 193/1,000 births (Cox, 2007). Prevalence estimates of high-risk First Nations communities in British Columbia and Manitoba reported rates of 190/1,000, and 55-101/1,000 births respectively (Robinson, Conry, & Conry, 1987; Square, 1997). Another study estimated incidences of FAS among First Nations children at 46/1,000 births in the Yukon and 25/1,000 in Northern British Columbia (Asante & Nelms-Maztke, 1985). In contrast, prevalence rates in urban Saskatchewan showed a rate of 0.589/1,000 births (Habbick, 1996). The large differences in these results indicate that certain communities may experience a higher risk of FASD, though incidences have also been shown to be present among all ethnic groups (May & Gossage, 2001). A U.S. based study indicated that prevalence of FAS among Native-American and, to a lesser degree, African-American ethnic groups were higher than in other groups (Chavez et al., 1988). Past and future prevalence rates, however, may be conservative as FASD tends to be under-identified due to reliance on self-report measures to render diagnoses (Sokol, Delaney-Black, & Nordstrom, 2003). Unfortunately, some of the prevalence rates noted above may also be inaccurate due to procedural problems,

such as inconsistent methodological practices across studies, and should be interpreted with caution (May & Gossage, 2001).

Outcomes for children with FASD are often discouraging, as youth with FASD, after diagnostic screening and assessment, are over-represented in the legal system (Fast, Conry, & Loock, 1999). In a recent study of a Manitoba prison, inmates were evaluated for possible FASD. The results indicated that, after individual assessments, incidence rates of FASD in prison were 10 times greater than that of the general population (Chudley, 2007). This finding is not surprising, as an estimated 60% of adolescents or adults with FASD experience trouble with the law (Streissguth, 2001). In contrast, a Canada-wide study of prisons showed a surprisingly low recorded incidence of FAS, at 0.087/1,000 (Burd et al., 2003). This result illustrates the need for screening, identifying, and managing offenders with FAS; none of the prisons in this study had an FAS screening procedure, and only 3 of 11 institutions had access to diagnostic services for FAS.

Defining a Behavioural Phenotype

FAS is considered the leading preventable non-hereditary cause of intellectual disability (NIAAA, 2000). In addition to the physiological signs of FAS described by Jones et al. (1973), signs of FASD include difficulties in regulating emotions (Coles, et al., 2000), executive functioning (Rasmussen, 2005), attention (Mattson, Calarco, & Lang, 2006), and behavioural challenges (Streissguth, Barr, Bookstein, & Olson, 1999). Persons with FASD are also at high risk of developing secondary disabilities such as mental illness and addiction (Streissguth, 2001).

Several researchers have recently undertaken the important process of attempting to define a behavioural phenotype for FASD. Most recently, Kodituwakku (2007) provided a review of many of the behavioural and developmental aspects defined in other studies. In sum, Kodituwakku, describes FASD as "a generalized deficit in processing complex information" (p. 199), and notes that central nervous functions are highly dependent on, and related to, adjacent functions. Thus, the assumption that other regions, that are not directly impacted by alcohol are functioning normally, is faulty. This conclusion highlights the many and varied possibilities of the teratogenic effects of alcohol on the fetus, and recognizes the immense complexity of defining a behavioural description for FASD.

Developing a behavioural phenotype of FASD has also been difficult because of the large range of possible deficits associated with the disorder (Pei & Rinaldi, 2004). In addition, differentiating children with FASD from those with other conditions is particularly challenging because they may present very similarly. For example, children with FASD and children with ADHD can demonstrate very similar attentional deficits and impulsiveness. The neuropsychological differences between these two disorders have been subject to scrutiny (O'Malley & Nanson, 2002). Differentiating between FASD and other disorders is especially difficult when confirmation of maternal alcohol ingestion is not available, as is often the case (Barr & Streissguth, 2001). Yet, even though symptomology of other disabilities may be very similar to FASD, it is important to distinguish FASD because the etiology and intervention for the disorder is often quite different. For example, when dealing with difficult behaviours associated with FASD, interventionists should consider

behaviour in terms of executive functioning deficits, and not wilful disregard (Green, 2007). In addition, natural and logical consequences, which tend to be effective interventions in ADHD, are not as effective when disciplining a child with FASD (Region 6, 2004). In this light, creating a behavioural phenotype for fetal alcohol spectrum disorder becomes paramount for proper detection and, subsequently, appropriate intervention.

Etiology

Prenatal exposure to alcohol can impact many aspects of the developing central nervous system, including processes such as neurulation, development of the prosencephalon, neuronal differentiation, and the formation of synapses (Kumada et al., 2007). A prevailing theory of the teratogenic effects of alcohol on fetal development involves interference with neuronal migration. Cells of the central nervous system are proliferated in early fetal development and then migrate to specific destinations of the brain, where they then differentiate to provide specialized cortical function (Kolb & Whishaw, 2003). Because of alcohol's interruption, or at least, interference of neuronal migration, important functional connections with other cells are impaired or entirely lacking. As a result of impaired or absent cortical and sub-cortical connections, functions associated with affected neuroanatomical regions can be deficient (Kumada et al., 2007).

The theory of alcohol's impact on neuronal migration has been suggested since the early days of prenatal alcohol research (Jones, 1975). How ethanol specifically impacts neuronal migration, however, has been subject to scrutiny. Studies have demonstrated that the rate of neuronal migration may be delayed with

exposure to ethanol (Miller, 1993). In addition, migrating neurons may even be displaced and never reach their intended destination (Rovasio & Battiato, 1995). As an example, alcohol inhibits calcium signalling in a dose-response manner, which in turn can interrupt or reduce granule cell migration (Kumada, Lakshmana, & Komuro, 2006). Prenatal exposure to ethanol could impact neuronal migration in other ways, such as cyclic nucleotide signalling (Kumada et al., 2007).

From autopsy studies, it was previously concluded that prenatal alcohol exposure impacted the central nervous system diffusely, in that the effects of ethanol on the brain appeared to be random. However, recent studies using enhanced neuroimaging technology have concluded that certain neuroanatomic systems seem to be particularly prone to prenatal alcohol exposure (Wass, Mattson, & Riley, 2004). For example, decreased growth of the cerebellum in relation to prenatal ethanol exposure has long been reported (Bauer-Moffet & Altman, 1975). Other structures that seem to be prone to prenatal alcohol include the basal ganglia (Mattson, et al., 1996) and the caudate nucleus (Cortese et al., 2006), which are involved in the enervation of purposeful movement, the corpus callosum (Sowell et al., 2001), which facilitates lateralization of cortical functioning, and the hippocampus (Berman & Hannigan, 2000), which is involved in memory. Because prenatal alcohol exposure is more likely to impact specific regions of the central nervous system, we would expect that functions associated with those high-risk regions would show more consistent deficits in the FASD population. Specific to the above-mentioned anatomical structures, children with FASD do show deficits in motor functioning (Janzen, Nanson, & Block, 1995) and memory (Rasmussen, Horne, & Witol, 2006).

In addition to sub-cortical structures of the central nervous system, prenatal alcohol exposure can impact cortical circuits and functioning. An area of study in fetal alcohol research involves evaluating the teratogenic impacts of alcohol on executive functioning, which involves higher order skills such as planning, inhibition, attention, problem solving, organization, and working memory (Rasmussen, 2005). Because executive functioning involves circuits in the prefrontal cortex, persons with FASD should show deficits in that cortical region. Studies have shown this to be the case. For example, persons with FASD, compared with controls, show less activation in the frontal-striatal circuit, resulting in a lack of inhibition (Fryer et al., 2007). Children and adults, with this lack of inhibition, will present with impulsive and stimulus-seeking behaviours, which has been a well-documented characteristic of FASD (Mattson, Schonfield, & Riley, 2001).

Measures of attention can reliably discriminate children with prenatal alcohol exposure. Lee, Mattson, & Riley (2004) compared children with prenatal alcohol exposure to controls using various measures of attention. Using these measures, over 90% of children from both groups were accurately classified as exposed to prenatal alcohol or non-exposed controls. This is consistent with the notion that deficits in attention are considered hallmark characteristics of FASD (Rasmussen, Horne, & Witol, 2006).

Different types of attention, in relation to FASD, have also been evaluated. Mattson, Calarco, & Lang (2006) concluded that children with FASD experience deficits in maintaining visual and auditory attention. However, alcohol-exposed children did not show deficits when they were required to shift between auditory and

visual stimuli. This finding demonstrates that certain aspects of attention (i.e. focused attention) may show greater impairment than others (i.e. shifting attention), and that attention should not be considered a unitary construct.

Neuroanatomically, attention is highly associated with the reticular activation system, which regulates sleep/wake cycles and levels of arousal. In addition, attention is involved with the frontal cortices, consistent with executive functions. Recently, the basal ganglia and corpus callosum have been recognized as playing a role in cognitive processes such as attention. Children with FASD can show abnormal development of frontal cortices, basal ganglia, and corpus callosum (Fryer et al., 2007; Mattson, Schonfield, & Riley, 2001; Mattson, et al., 1996), and these deficiencies in neuroanatomical development likely contribute to attentional difficulties.

Deficits in attention in childhood have also been shown to correlate with future antisocial behaviour. Pardini, Obradovic, & Loeber, (2006) found that inattentive tendencies in 4th graders predicted future delinquency. Other studies have shown a strong relationship between Attention Deficit, Hyperactivity Disorder (ADHD) and Conduct Disorder (Fischer et al., 2005). These studies, however, tend to consider ADHD as a whole, without partialing out non-attention aspects of the disorder such as impulsivity.

Inhibition, like attention, is not a strictly localized function. Rather, aspects of inhibition are distributed throughout the frontal cortex. Specific aspects of inhibition, however, show greater specialization with associated cortical regions. For example, the type of inhibition enervated by the orbitofrontal circuit involves the regulation and

mediation of social and emotional responses, much like the major function generally associated with that region (Zillmer, Spiers, & Culbertson, 2008). Neuroanatomically, the orbitofrontal cortex shares connections with the amygdala, rendering a strong emotional component to the system (Happaney, Zelazo, & Stuss, 2004).

Dysfunction of social/emotional inhibition is particularly concerning because it can be associated with low frustration tolerance, lack of empathy, and even violent behaviour. Subsequently, damage to this region is associated with antisocial behaviour. Neuroimaging studies of antisocial disorders (i.e. antisocial personality disorder) indicate decreased activation in the orbitofrontal cortex and corpus callosum, a smaller hippocampus, and reduced gray matter in the frontal cortex (Bassarath, 2001). Neuroimaging studies of FASD have demonstrated that all these areas are also prone to prenatal alcohol exposure (Spadoni et al., 2007). In addition, Bassarath (2001) anticipates dysfunction of the Basal Ganglia may also play a role in antisocial behaviour, which is another characteristic frequently found in FASD (Mattson, et al., 1996).

An additional challenge associated with disinhibition includes environmental dependency syndrome, which is the tendency to engage in stimulus-bound, or utilization, behaviour. In their study of children with ADHD, Archibald et al. (2005) postulated that striatal regions of the frontal cortex are associated with utilization behaviour. This can cause disruptions in attention, especially in learning environments such as school. In addition, the stimulus-bound individual may experience difficulty maintaining social relationships because, often, stimulus-bound

behaviour is not considered socially appropriate as it can be intrusive (Archibald, Mateer, & Kearns, 2001). Children with FASD also show dysfunction in the frontal-striatal regions of the cortex (Fryer et al., 2007) and may be prone to engaging in similar stimulus-bound behaviour.

A critical component of the orbitofrontal cortex involves learning from external consequences. By monitoring consequences to purposeful action, the orbitofrontal cortex assists in directing future behaviour. Consequential learning is impaired in FASD (Streissguth, 1997), perhaps as a result of this neurological deficit. In addition, the orbitofrontal cortex involves learning and adjusting behavioural responses in relation to changing social contexts. Thus, orbitofrontal damage can impair social learning and cognitions, and consequently impact social relationships (Zillmer, Spiers, & Culbertson, 2008). Similar social deficits are found in relation to FASD, as children and adults with the disorder often have difficulty creating and maintaining friendships. They have difficulty understanding subtle social cues and have trouble adjusting their behaviour in light of novel social situations (Region 6, 2004). For this reason, children with FASD often need extra cues to help them navigate social situations, such as simple, concrete rules, and practicing via role play. In addition, parents and caregivers may need to educate and arrange friendships with responsible peers (Region 6, 2004).

Emotional processing is considered a relatively new area of study in neuropsychology. This is probably the case because, until now, emotions were considered unimportant compared to pure cognitive processing. Emotions were also thought to be completely separate from cognition. Now, emotional processing is

considered a critical factor in navigating the environment because we live in a social world. Modern research has indicated that healthy emotional functioning also assists in cognitive processes (Zillmer, Spiers, & Culbertson, 2008). Navigating our social world requires the ability to understand others' emotions, to be able to regulate our own emotions, and to be able to learn from and respond to social interactions.

Like other cognitive process, emotion is not strictly localized, but functions within a system. Traditionally, the limbic system has been thought to underlie emotional processes, with the amygdala as the centrepiece. The amygdala, and to a lesser degree the anterior cingulate, is involved in primary emotions such as fear. Primary emotions can motivate behaviour in more than one way. For example, the amygdala can receive direct projections from the thalamus when a rapid response is needed, such as when a person needs to quickly escape a potentially dangerous stimulus, such as an intruder. Conversely, sensory projections from the thalamus can also cross cortical pathways before reaching the amygdala (Zillmer, Spiers, & Culbertson, 2008). This route is useful when a more precise interpretation of the stimulus is needed, such as the realization that a supposed intruder is actually a decorative tree (I can personally testify to that effect).

Little research has implicated dysfunctional amygdalae prenatal alcohol exposure, although the hippocampus, directly inferior to the amygdala, has been implicated (Mattson, Schonfield, & Riley, 2001). The hippocampus and amygdala, however, are complementary structures. Therefore, since hippocampi are susceptible to prenatal alcohol (Berman & Hannigan, 2000), people with FASD could experience secondary deficits in amygdalaeic functioning. In this way, processing, regulating,

and interpreting emotion may be impaired, not necessarily the experience of emotion. Studies of FASD (Coles, et al., 2000) demonstrate impairments in emotional processing and self-regulation, but little recent research has implicated the amygdala (Kim et al., 1994).

Unfortunately, antisocial behaviour and conduct-related disorders are commonplace amongst those prenatally exposed to alcohol (Schonfield, Mattson, & Riley, 2005). Such antisocial behaviour amongst FASD populations can lead to serious moral violations, such as sexually offending behaviours. Baumbach (2002) recommends that sexual offender assessments ought to incorporate an evaluation of possible prenatal exposure to alcohol, as he found that 49% of adolescents and adults with FASD repetitively demonstrate sexually inappropriate behaviour.

As noted, persons with FASD can have mild to serious cognitive challenges (Mattson, Schoenfield, & Riley, 2001), which can lead to behaviour problems and secondary disabilities such as antisocial and conduct disorders (Streissguth et al., 2004). Deficits in cognitive processes such as attention, executive functioning, and emotional processing can lead to behavioural challenges and delays in adaptive functioning and socialization (Kodituwakku, 2007). In addition, mental illness and addiction can result from these cognitive and executive deficits (Streissguth, 2001). However, delays in cognitive, executive, and emotional processing, as well as secondary disabilities, can also be influenced by the environment. For example, children with FASD who are diagnosed early and raised in stable home environments have been shown to be more apt in avoiding disruptions in school, trouble with the law, confinement (i.e. prison), repeated inappropriate sexual behaviours, and future

alcohol/drug problems (Streissguth et al., 2004). It is therefore not surprising that Canadian Federal and Provincial governments consider FASD family support to be an important priority (Chudley et al., 2005, Public Health Agency of Canada, 2006).

Chapter III

Study Design, Data Gathering, and Analysis

Parenting children with FASD

Adolescents and adults with FASD are at increased risk of disrupted school experience, trouble with the law, confinement (i.e. prison), inappropriate sexual behaviours, and alcohol/drug problems. However, individuals with FASD provided with an early diagnosis and a stable home environment are significantly less likely to engage in these considerable social problems (Streissguth et al., 2004). The authors concluded that "good stable families, with enduring relationships with their children with FAS/FAE, appear to be a critical protective factor for helping children avoid adverse life outcomes" (p. 237). For this reason, it may be important to provide support that will promote stable environments for families with FASD children.

Children's cognitive deficits, behavioural difficulties, and secondary disabilities, however, can cause considerable challenge for parents raising children with FASD (Brown, & Bednar, 2003). The Public Health Agency of Canada has called for increased research on the circumstances and experiences of mothers who consumed alcohol during pregnancy (2006). In addition, research comparing the experiences of birth and adoptive parents raising children with FASD is needed to ascertain facilitating factors and barriers to successful family functioning (Frankel, Frankel, & Opie, 2007). Research of this nature should enable better understanding of the factors that promote or hinder successful family functioning with children with FASD.

Frankel, Frankel, & Opie (2007) interviewed parents who were perceived as successful in parenting children with FASD. In their study, the researchers described a plethora of challenges in caring for children with FASD, such as children's behavioural, cognitive, affective, physical, developmental, and social functioning. In addition, the researchers described several barriers to successfully accessing supports from educational and health care systems, and other external sources of stress such as racism and loss of culture among aboriginal children in non-aboriginal homes.

Brown & Bednar (2004) evaluated parents' challenges raising children with FASD, and organized participants' responses into eight concepts. Parents expressed difficulty preventing the child's behaviour problems before they occur; making time for themselves; keeping plans for themselves and their families; collaborating with the school to maintain consistency for their child; keeping the FASD child involved in community activities; lacking support from professionals; keeping their child involved with peers; and coping with learning and behaviour problems. Challenges of parents raising children with FASD are varied, and multiple factors may accumulate to increase overall parenting challenge and stress.

Higher levels of stress may be experienced in families where children with prenatal alcohol exposure are raised. Paley et al. (2006) evaluated predictors of stress in 100 children with FASD and their parents. In this study, the researchers compared children's cognitive, executive, adaptive, and behavioural functioning with child and parent domain stress, accounting for demographic, diagnostic, and resource variables. Paley et al. found that delays in executive functioning, impaired adaptive functioning, behavior problems, and adoptive parent status were related to higher child domain

stress. Parent domain stress was associated with biological parent status and fewer family resources. Interestingly, cognitive functioning did not predict parent or child domain stress. These children's scores on the Kaufman Brief Intelligence Test (K-BIT), a brief measure of verbal and non-verbal intelligence, yielded a mean of 97.24 (SD=14.83), close to the standardized mean of 100 (SD=15). This suggests that higher cognitive functioning may mediate child or parent domain stress. It also suggests that, although children with FASD tend to demonstrate lower cognitive ability overall (Mattson, Schonfield, & Riley, 2001), encountering children with average cognitive ability may not be unusual. The authors concluded that support for both children with FASD and their parents are needed to mediate these factors, which may lead to decreased parent and child domain stress.

Because a stable family environment is key to helping children with FASD attain positive outcomes (Streissguth et al., 2004), additional supports for parents are needed (Brown & Bednar, 2003). Supports needed by families raising children with FASD, described by Brown (2004), include a broad support network of family and friends; helpful and compassionate professionals who have a good knowledge of prenatal alcohol effects and available community resources; a good working relationship with the child's school, including staff with knowledge of FASD and appropriate strategies to promote learning; income support to assist with expenses such as medical costs and respite; and a strengths-based approach to parenting, taking into account the individual child's unique abilities and challenges.

A couple of parenting FAS studies using a qualitative approach were retrieved from the literature. Granitsas (2004) conducted unstructured interviews with four

adoptive parents who were currently caring for children or adolescents with FASD in their homes. Using a phenomenological-hermeneutic approach for data analysis, six essential themes emerged from the interviews: Feeling Delight Upon Adoption, where parents described their joy in adding an adopted child to their family; Not Knowing, where parents explained that they were given no information, or incomplete information about their child's diagnosis; Identifying Problems, Concerns, and Difficulties common to FAS; Feeling Frustrated given difficulties raising a child with FAS; Feeling Pride in children' accomplishments despite medical, learning, and behavioural challenges; and Feeling Devoted despite incomplete knowledge, frustration, and coping with difficulties. Granitsas, who adopted four children with FAS, then compared and validated the participants' experiences with her own. Recommendations for nurse practitioners serving parents of children with FAS include reviewing maternal alcohol consumption for prevention of FAS, serving as resources for parents, being empathetic advocates, and assisting with individual educational plans and parent advocacy.

Gardner (2000), who described experiences of eight foster parents of children with FAS, also used an unstructured interview format. Using content analysis, Gardner described three topic areas: Cognitive concerns (diminished memory/comprehension, lack of understanding consequences, absence of fear); Behavioural management (hyperactivity, aggressiveness, destructiveness, decreased sensation of pain), and Coping with daily realities (necessity of providing consistency, coping strategies, fears for the child's future). Cognitive concerns and behavioural management related to Effects on the Child, and Coping with daily

realities related to Effects on the Foster parent. Gardner recommended that nurses help parents create realistic expectations for their children, and to assist parents in recognizing that misbehaviour is due to brain dysfunction, not maliciousness.

Granitsas (2004) and Gardner (2000) provide important insight into parents' experiences raising children with FASD. However, both studies are limited in that only non-biological parents were interviewed. Biological parents' experiences may be unique in some ways, and warrants further exploration. Parents were only included if their child was presented with full blown FAS, meaning that parents of children with other disorders on the fetal alcohol spectrum were not included. Because only families with FAS were included in these studies, families were included partly based on children's facial dysmorphology, which is relatively unimportant compared with central nervous dysfunction (Chudley et al., 2005). In addition, of all children with FAS in these studies, none were adults, and none lived out-of-home. Although these procedures were beneficial in that demographic variables were well-contained, perspectives of parents whose children FASD but not FAS, or whose children lived out of home, were lacking.

Method

Design

To explore biological and non-biological parents' experiences raising children with FASD, a phenomenological-hermeneutic approach was utilized (Van Manen, 1990). Rehorick & Taylor (1995) articulated the need to understand human experience "as-is" which, in terms of parenting, may include parenting expectations and stresses, as well as coping with children's behavioural and cognitive challenges.

The "as-is" experiences of parents are not restricted to positivistic, observable incidences and experiences. Rather, un-observable cognitive processes permeate human experience (LeVasseur, 2003). In order to prevent leading participants to share particular experiences and to enable the sharing of "as-is" experience, an unstructured interview format was followed, using such questions as "Can you tell me what it was like raising ___ in your home?"

Ethical Considerations

The University of Alberta's Research Ethics board for Education and Extension reviewed and granted approval for the study. Identifying information of participants has been removed, and the names of parents and children appearing herein are pseudonyms.

Participants

Parents were eligible to participate in the study if they presently, or had previously, raised a child with FASD in their home, and could speak English. In total, 11 participants, consisting of biological (3), adoptive (7), and foster (1) parents were recruited through community agencies and word of mouth in an urban Alberta city and environs. Three adoptive parents and one biological parent cared for children who now live out-of-home. All participants were Caucasian except for Lorraine who was Native American. Age range of the participants was 32-59 years, with a mean age of 45.8. Table 1 contains demographic information on the parents, including age, employment, marital, and parental status, and the ages of their children with FASD.

Table 1 - Participants

Participant (pseudonym)	Age	Current employment	Marital status	Parental status	FASD child(ren) (pseudonym)
Allison	52	Part-time custodian	Separated	Adoptive	Andrew (age 16)
Bob	59	Manager	Married	Foster	Becky (age 14), Beth (age 12), Brianne (age 11)
Christine	33	Stay-at-home parent	Married	Adoptive/Step-parent	Chad (age 6)
Deidre	32	Stay-at-home parent	Divorced	Biological	Dylan (age 15)
Ellen	50	Behaviour consultant	Divorced	Adoptive	Elizabeth (age 21)
Frances	57	Social worker	Divorced	Adoptive	Fraser (age 18)
Gloria	47	Occupational therapist	Married	Adoptive	Gavin (age 12)
Jane	46	Executive assistant	Married	Adoptive	Jeremy (age 18)
Karen	33	Community FASD worker	Single	Adoptive	Kevin (age 5)
Lorraine	56	Family support worker	Married	Biological	Larry (age 20)
Mark	39	Stay-at-home parent	Married	Biological	Mary (age 11), Makayla (age 10)

Data Collection

Participants in this study were recruited through an FASD newsletter received by approximately 1,300 Albertans, through community agencies, and through personal contacts. Once a participant demonstrated interest in the study, the researcher arranged an appointment at a private location of the participants' choosing. An explanation of the study was provided, and informed consent was obtained. The participant then completed the Parental Expectancies Scale (Eisen et al., 2004). Following this brief 20-item survey, the participants were instructed that the interview would be audio recorded, and that the interviewer was not looking for specific

themes, but wanted to know parents' experiences from their perspectives. Participants were asked to share thoughts and experience important to them. Each interview commenced with the interviewer asking a question like, "What has it been like raising _____ in your home?" At the conclusion of the interview, the interviewer asked the parents to sum up their experiences "in a phrase or two." These interviews lasted from 30 minutes to an hour each, and were transcribed verbatim for analysis.

Data Analysis

The researcher examined the interview transcriptions for emerging themes (Van Manen, 1990). QSR Nvivo 7 ® qualitative data analysis software was used to help identify, categorize and compare the themes. As themes emerged they were organized into central themes and sub-themes. Quotes were identified that seemed best to describe these themes. To assist with the identification and coding process, some themes were named after a quote provided by a participant. In this way, interpretation and organization of themes remained close to the data, and allowed the data to "speak for itself" (Osbourne, 1990, p. 81). To improve trustworthiness of the data analysis, I shared the themes with three of the participants to determine if my interpretations were congruent with their perspectives. These three parents expressed that they felt the themes were accurate.

Chapter IV

Findings and Discussion

Nine central themes were derived from the interviews: 1) something's not right; 2) receiving a diagnosis; 3) attitudes toward birth parents; 4) living in a war zone; 5) understanding my child; 6) getting support; 7) re-defining success; 8) lifelong parenting; and 9) my child's gifts. Sub-themes were derived from several of these central themes. Explanations of central and sub-themes are provided as data from each are presented.

"Something's not right"

Except for Karen, all non-biological parents in this study had taken their children into their homes prior to a diagnosis of an FASD. Some of these parents were unaware that their child's birth mother consumed alcohol during pregnancy. For example, Jeremy's birth mother denied consuming alcohol during pregnancy to Jane (the adoptive mother) at the time of adoption, but later admitted that she consumed alcohol years later in light of an FASD diagnosis. Other parents, while aware that alcohol was consumed during pregnancy, were uninformed of the potential impact on their child's cognitive, learning, and behavioural functioning. Although he was aware that his foster children demonstrated developmental impairments and that their birth mother consumed alcohol during pregnancy, Bob explained that, "we didn't even know what fetal alcohol effect was all about at that point in time." Allison recounted she found out Andrew's birth mother used substances after she already signed the adoption papers:

> After we signed the adoption papers, the social worker says 'by the way, we found out that his mom used to drink and do drugs', and that was it. That is all she mentioned. I didn't have a clue what FASD was.

Parents' journeys to obtaining a FASD diagnosis began as they perceived that "something was not right" with their children. Deidre explained that Dylan was kicked out of day cares and that, "his behavior toward other children didn't seem right." Christine started caring for Chad when he was one year old, and soon was, "starting to realize there's something not right with his life." Jane noted that "all kinds of things were happening, and we just knew it wasn't right." Frances described how Fraser seemed "out of character" when he was seven years-old:

> Well that's when things started falling apart when he was 7...he just became very aggressive and he became quite delusional...he became extremely impulsive...he also made this suicidal gesture that he had a tensor bandage and he kind of wrapped it around his neck and it wouldn't have worked but at 7 years old I don't think he necessarily knew that. So he was in a lot of distress and he was aggressive it was totally out of character and that's when we really knew there was something wrong...It was really stressful because we really didn't know what was happening. We had no real explanation of any kind. It just didn't seem to make sense.

Seeking answers

Several parents started seeking answers as they perceived that "something was not right" with their children. For some of these parents, investigating the possibility of prenatal alcohol exposure was a self-directed exploration. Frances did some

reading on the effects of prenatal alcohol exposure to "try to figure out what was going on" with Fraser. Mark's father explained to him the signs of FAS, which gave him "another idea of what [his children] had." Jane read material on FASD provided by her employer and explained that, "it was like reading our story in a lot of ways." With her background in occupational therapy, Gloria suspected that FASD may have been a factor in Gavin's life and initiated the process of diagnosis:

> We started to have some extreme behaviours after he moved in. In my mind, I thought 'is this fetal alcohol?' Because he was exposed prenatal to alcohol and all kinds of drugs. We had that documentation so I started to think maybe this is what it is, so I got him in the [hospital] to get the diagnosis."

"Not on the radar"

Some parents encountered barriers as they were seeking answers to their children's apparent deficits. Several participants indicated that prenatal alcohol exposure was "not on [the doctor's] radar screen", and that aberrations in behaviour and development were dismissed as "nothing to worry about."

Gloria and Jane, with backgrounds in occupational therapy and disability, respectively, suggested to their physicians that FASD may be a factor contributing to their children's cognitive and learning challenges. Christine's doctor told her "don't worry about it" when she explained the possibility of prenatal alcohol exposure for Chad. Frances expressed frustration with the lack of awareness of FASD exhibited by some mental health professionals:

> Nobody seemed to be cognizant of fetal alcohol...It's really frustrating for parents because for the most part you're dealing with mental health

professionals who are absolutely clueless about fetal alcohol. It's not on their radar screen.

Receiving a diagnosis

Receiving a diagnosis of FASD seemed like a double-edged sword for many parents in this study. Birth mothers experienced grief and guilt for drinking during pregnancy. In addition, biological and non-biological parents expressed regret for "mishandling" situations before they were aware that their children were impacted by prenatal alcohol exposure. However, obtaining a diagnosis provided relief and validation as parents came to understand their children's challenges. Finally, several parents explained that an FASD diagnosis was not the only identified concern, and that they were faced with a "double whammy"; having to cope with multiple disabilities.

Grief and guilt

Mark had difficulty accepting his girls' diagnosis of FASD and felt "overwhelmed." Ellen explained that she felt "incredible guilt" for assuming her daughter was purposefully misbehaving. Lorraine explained that, "if I could do it all over again and know the things I knew before hand I wouldn't have [drunk alcohol during pregnancy]." Deidre described the terrible guilt she felt when she learned that Dylan's deficits were the result of drinking during pregnancy:

> I had a lot of guilt for many years...very much depressed, knowing that my drinking caused this damage. Like I said, that just threw me over the edge. I cried a lot. I felt bad that I did this damage to Dylan. I thought what kind of a parent am I to do that to my own kid.

Jane experienced a grieving process as her hopes and dreams for Jeremy were spoiled:

> There was a prolonged grieving stage because you have all these hopes and expectations for your child that they're going to grow up and be successful and have relationships, and you can certainly never expect that at 15 you're going to be moving your child out of your home, and you're going to be dealing with the justice system and professionals and ultimately having your 18year-old son go to jail, having to talk to street people in order to find out where he is. All of those things were not hopes and dreams you have when you have a small baby.

Relief and validation

Although parents experienced feelings of regret and grief, receiving a diagnosis also provided relief and validation as they came to understand the source of their children's challenges better. Ellen felt "a great comfort" when she received the diagnosis. Deidre and Christine explained that the diagnosis made the behaviours "more understandable." Because she better understood Chad's behaviours, Christine added that she "could deal with it better." Allison said that receiving a diagnosis provided insight regarding what to expect of Andrew:

> At first I figured we were doing something wrong because he is not listening. Then after he was diagnosed and we went to the [hospital] and they said he also has oppositional defiant disorder, then we kind of realized where he was coming from. And then the more we learned about his diagnosis and the

impact of what to expect and what not to expect, then it was easier to a certain degree...At least we knew what we were in for!

Double whammy

Several parents explained that their children had other disabilities and disorders in addition to FASD. As noted in the quote above, Andrew was diagnosed with Oppositional Defiant Disorder in addition to FASD. Elizabeth was previously diagnosed with Generalized Anxiety Disorder, and Fraser also experienced significant concerns with anxiety. Chad was diagnosed with ADHD prior to FASD, and also experienced separation anxiety. Kevin was not responding to family members and was diagnosed with Reactive Attachment Disorder. Becky was given an additional diagnosis of ADHD, and Beth demonstrated obsessive/compulsive tendencies. Gavin has Cerebral Palsy and Post-Traumatic Stress Disorder in addition to FASD, and Larry was diagnosed with Klinefelter's Disorder. These factors, in relation with FASD, create a complex profile for these children.

Dealing with multiple disabilities, however, is not limited to the children diagnosed with a FASD in this study. For example, Mark, who has two biological children with FASD, is also the step-parent of a child with developmental delay and aggressive behaviours. In fact, his greatest challenge in parenting is coping with his step-son's aggression, not dealing with Mary's and Makayla's deficits. In addition, Jane's biological daughter has been diagnosed with Post-Traumatic Stress Disorder, and Christine's step-daughter deals with an eating disorder. In this way, parents face additional challenges in raising their children.

Attitudes toward birth parents

Several non-biological parents, and a biological father, shared their feelings and perceptions toward their children's birth mothers. Although this topic was not anticipated at the commencement of the study, it does provide important insight into the feelings and perceptions of adoptive/foster parents of children with FASD. Some parents expressed anger toward their child's birth mother for "ruining" their child's life. They were frustrated that some mothers drink alcohol during multiple pregnancies with impunity. Other parents withheld judgment and acknowledge probable challenges in the birth mother's life that may have contributed to her drinking. They suggest that FASD is a greater social issue than a woman's individual choice to drink, and suggest that these birth mothers do not set out to intentionally harm their children.

Ruining lives with impunity

Brian, who fostered three siblings with FASD, expressed frustration with the tendency for some biological mothers to repeatedly drink across multiple pregnancies:

> These children are really given a life sentence. It's really tragic. It's sad. It's pathetic what mothers are allowed to do to their children, you know, without any impunity they can have one child after the other, damage the one, have another one, damage that child, another and another and another. And the focus is always around the poor parent. I mean that's valid to some extent but God there should be a time when there comes a time to take some responsibility or responsibility asserted on them, you know, because how many kids are damaged this way? The mother will have a half a dozen

children, screw them all up, give them a life sentence of hell in so many ways…I wish our society could do something, address that, the larger issue, put more attention into that because it's sickening what is allowed to go on.

Christine, who related that her son will likely spend time in jail as an adult, equates drinking during pregnancy with child abuse:

> She smoked dope and she drank and they're both evil. I mean they've ruined his life pretty much…So I get really angry at her because his life didn't have to be that way, and I mean, like he is hard to deal with…the parents don't really get consequences for it and I have, I find that really unforgiving that if you beat your child or you shake your child, you go to jail or you get charged or whatever. But if you drink when you're pregnant because it doesn't count as a baby yet and you give that kid FAS…nothing happens to you. To me there's no difference.

Mark, the biological father of his two children with FASD, is reserved about forgiving his girls' birth mother:

> I don't think I fully forgave her, but I think the reason I don't forgive her is she damaged the girls' life, they have it the rest of their lives, later on in the future and even to this day I have to fight to get better education for them and the help they need…They always talk about how good their mom is and stuff like that, a lot of times I have to bite my tongue.

Unintentional harming

When asked what she would say if she met her child's birth mother, Gloria seemed careful to respond without judgment, but would be reserved in sharing her child's successes:

> (long pause) I guess I'd say that…I tell her that he's okay, and that things will work out…Maybe I'll tell her she didn't screw up that badly, cause he's a great kid. I'm sure she had her own problems that caused her to do what she did. But he is, just wonderful, fantastic kid. Yea, I don't know if I'd tell her how fantastic he is but I'd tell her he's a good kid.

Jane explains that her son's birth mother was in an abusive relationship, which may have contributed to her drinking alcohol during pregnancy:

> There are various reasons why people make choices. I think that her choice was unfortunate, but I don't think that it's my place to judge her. I know very, very little about her relationship with (my son's) biological father. It was not a good one. He was a very violent man. We suspect that some of (my son's) issues are mental health issues that actually are hereditary and he likely got from his birth father…Certainly what I do know about the birth father is he spent most of his life in and out of jail. Very antisocial behavior. She may not have realized she was pregnant, the stress of raising two children, living with a violent man. I mean, there's all kinds of things.

Karen speculates that birth mothers do not intentionally harm their babies, and that drinking alcohol during pregnancy is only part of the FASD problem:

> I don't know if those are necessarily choices. I think these addictions are so strong and so powerful for women…I don't feel bitter toward women who

drink during pregnancy, I don't feel angry towards them because I don't believe that any women sets out to intentionally harm their baby. They don't set out with that, they don't think okay I'm pregnant, I'm going to do as much damage to this kid as I can…And I think even when they are women in her circumstances that are so caught up in this world of addiction, and it's not just with alcohol, it's the whole life, the poverty, the drinking, the drugs, the homelessness…It's not so easy just to separate that and say stop drinking. These people need help and counseling and things like that. Not necessarily that they will drive her to drink, but it's so ingrained in them, it's part of who they are.

"Living in a war zone"

Many children with FASD demonstrate severe behavioural challenges, including tantrums, aggression, and destructiveness (Mattson, Schonfield & Riley, 2001). In this theme, parents describe their experiences living and coping with their children's tantrums, aggression, and destructive behaviour. For several families, coping with these significant challenges have impacted family members' mental health and relationships, and are described in the sub-theme *"Collateral Damage"*. In addition, chaos in the home is further fuelled in some cases when parents are "not on the same page", which is described in the sub-theme *"Two Generals, One Army"*.

Bob explained that his children "would just explode." Christine noted that since living with six year-old Chad, he has cracked her tooth once and has broken her nose four times. Allison had to get rid of the family dog because "Andrew would be pulling its tail and biting the dog, and picking the dog up and just throwing it." Jane

explained that living with Jeremy was "like living in a war zone." She further noted that, "Anything could trigger him, and he would go on a rampage, and he would break things, and if anybody got in his way even the slightest little bit he became violent." Gloria shared an experience where seven year-old Gavin tantrummed for 11 hours:

> My husband and I took turns restraining him. So you go have supper and I'll hold him down, and then you, that's how we did it. This time it was 11 hours, and it was 11 at night and we were so tired…My husband had to put Plexiglas up over the window because we were afraid he was going to smash the window. We hear this huge crash, so we go up, and he'd managed to get the Plexiglas out of the window, and he'd broken it into 100 little pieces.

Challenges in learning and memory associated with FASD may impact contingency learning (Streissguth, 1997). For this reason, behavioural strategies, such as natural and logical consequences, are often ineffective in modifying behaviour. Karen explained how implementing natural consequences did nothing to reduce Kevin's hitting:

> He's had so much behavior management and work put into him…I don't even think it's to the point that he's gotten better. I think we've learned to not set him off…He'd hit constantly. Before I had any formal training in FAS I would try natural consequences. So he would hit me and I would put him in timeout on a chair. And I even taught Kevin, you hit you sit. That was the rule. I trained him to sit down after he finished hitting. So it's all he did, I just

trained him. So he would hit and he would go sit down in the chair, but the consequence didn't stop the hitting.

Collateral Damage

"Living in a war zone" can create a chaotic home environment where "its very hard to make a family seem like a family" (Frances). In the theme *Collateral Damage*, parents describe the impacts of this environment on family members' feelings, mental health, and relationships.

Bob shared that fostering children with FASD has impacted his "social life significantly." Christine notes that her other step-children were embarrassed and missed out on many activities due to Chad's behaviour. Jane explains that her daughter was diagnosed with Post-Traumatic Stress Disorder as a result of Jeremy's violence in the home. Frances noted that her experience raising Fraser has tainted her perspective toward people affected by prenatal alcohol exposure: "I can't even say I can learn how to get along with a fetal alcohol kid because sometimes when he gets really aggressive, it's really hard to accept the behaviour. It's influenced my attitude."

Two Generals, One Army

This theme describes the turmoil that can result when two parents raising their child with FASD are not "on the same page." At times, one of the parents seemed to have difficulty accepting their child's limitations which, according to some participants, created additional strain on the marital relationship.

Gloria explained that "there are still control issues" in raising 12 year-old Gavin. Lorraine felt that her husband does not support her in terms of Larry's disability and said that it is "hard on me." Jane indicated that her husband, Jeremy's

step-father, is not "used to living with somebody with FAS, and it's very chaotic. He figures that rules will fix the problem, and rules don't always fix the problem." Allison, who has been separated from her husband for 10 years, described the impact these challenges had on her marriage, which eventually contributed to their breakup:

> We worked together when we adopted Andrew, and once all his behaviours started we couldn't take it anymore. So [my ex-husband] said either Andrew goes or he goes. So I had a tough choice to make. I couldn't get rid of him. Because he was already disposed of once. I couldn't do that again.

"Understanding my child"

Parents reported that their abilities to care for their children improved as they learned about the behavioural, cognitive, and developmental impacts of prenatal alcohol exposure. However, learning about FASD was only one step toward more successful parenting. Because of the spectrum of deficits associated with FASD, the impacts of prenatal alcohol exposure are unique to each child, and deficits associated with the disorder will not manifest in all cases. In addition, parents related that even when well-versed in knowledge of FASD, appropriate strategies were difficult to implement when coping with parenting stresses and "losing patience" (Gloria).

Bob explained that "real learning" about FASD children doesn't come in a book, but in hands-on experience: "You can read about fetal alcohol. You see the images and you can understand that they're affected physiologically and intellectually and, whatever. But your real learning is about how you deal with these children."

Six sub-themes were identified as part of parents' learning about their children: 1) here today, gone tomorrow; 2) an invisible disability; 3) trouble

maintaining school/employment; 4) taken advantage of; 5) in the wrong crowd; and 6) creating a bubble.

"Here Today, Gone Tomorrow"

Ellen described Elizabeth's tendency to forget simple tasks, such as putting on socks, as "here today, gone tomorrow." This theme describes parents' perceptions of the learning and memory challenges their children experience. Several of these children often require frequent cueing, reminding, and re-learning of even simple tasks. Parents shared their frustrations with their children's memory and learning, how they came to understand these challenges in relation to FASD, and how it has altered the way they parent their children.

Deidre explained that Dylan's "mind doesn't click" and that teaching him "will always be 2 steps back and a step forward." Jane described that 18 year-old Jeremy "can't even look up somebody's phone number in the phone book alone." Christine was baffled by her son's apparent inability to learn:

> It's a really hard thing to get your head around when you realize that he really doesn't understand. You're telling him this and he really doesn't get it. But he understood it yesterday…He got it. Then today it's like you've never told him at all because he doesn't remember. That's really hard to understand how come, well you knew yesterday, why don't you know today?!

Ellen was confused as to why her teenage daughter had trouble completing simple tasks:

> Why hasn't she gotten it? We've done it a million times. Why can't you do this? Even as a teenager, I'd say can you put on the kettle for me, and she'd

> get to the top of the stairs and you knew she forgot what she went for. We are talking from here to there and its gone. Kettle. Then she'd go put the kettle on. There is a period of time where that drove me crazy, she couldn't remember to go put the kettle on, or whatever it was. Put your socks on. Walking around with a sock in her hand without a clue that she should put it on her foot.

Coping with such memory and learning challenges can be wearisome even when the parent knows that their child is experiencing a memory or learning deficit. Christine explained that, "it's frustrating because you get mad telling your kid the same thing a million and one times but you know he doesn't remember." Although well-versed in understanding the deficits associated with FASD, Gloria sometimes loses her patience with Gavin's inability to complete simple tasks:

> Just understanding for the umpteenth time. Sometimes I am telling him things 7 times! Pick your shoes up! He'll go to pick his shoes up, but then see something else. And I say pick your shoes up. And then the phone will ring and he'll get it. It's like I'm going to scream! I'm really going to lose it. So it's hard even for me sometimes to keep my patience.

"An invisible disability"

Many people with FASD do not demonstrate the growth deficiencies and facial dysmorphology associated with FAS, yet can still demonstrate significant learning and behavioural challenges (Mattson et al., 1998). In some cases, people with FASD demonstrate average or above average IQ (Odishaw & Snart, 2005). The

invisibility of disability in these cases of FASD can lead to unrealistic assumptions and expectations about their social, learning, and behavioural functioning.

Lorraine explains that Larry's extended family believes that "he's smarter than what he is." Bob observes that Becky demonstrates "seemingly such intelligence" despite an IQ in the low 80s. Christine notes that some other disabilities such as Down's syndrome are visible, but that her step-son with FASD "looks totally normal." Ellen explains that people expect too much of Elizabeth, partly because she is not visibly disabled:

> I think in many ways she would have had an easier life if she looked more disabled…So her biggest issue is that people expect too much of her, because she looks like she (understood) and should be able to do it. That's what gets her in trouble. She does a lot of masking. She tries really hard to make it look like she knows what's going on, and half the time she doesn't."

In contrast, Gloria feels that Gavin, who also has cerebral palsy, will be advantaged throughout his life because he looks disabled, "I think in that way people will look after him a little bit more, he'll be a little more protected than someone with FASD that has an IQ of 100, who looks like he doesn't have a disability."

Trouble maintaining school/employment

Research indicates that people with FASD are at-risk of school drop-out and tend to have difficulty maintaining employment (Streissguth, 2001). Such struggles were demonstrated in this study as parents described their children's challenges with maintaining school attendance and finding and maintaining employment.

Jane related that Jeremy was kicked out of multiple school districts for "a variety of issues." Several parents, such as Deidre, had to deal with multiple suspensions and sought out specialized school programs to meet their children's educational needs. Allison explained that Andrew, who she described a "follower", exposed himself on the bus after his peers convinced him to do so. This action resulted in a school suspension.

Of the 4 adult children in this study, only Elizabeth graduated high school. This was surprising yet satisfying for Ellen, "she actually graduated high school which blew me away. I never thought that would actually happen but she did." Although she spent some time unemployed and receiving provincial funding from AISH (Assured Income for the Severely Handicapped), Elizabeth has successfully maintained employment:

> She also had approval for assured income, and she used assured income until the last year. She really needed it. She wasn't working any kind of regular shifts, she wouldn't accept any employment help as in going with an agency. So she'd get these jobs, one of them was a cashier, and there is no way. She can't count money. Not at the speed that you need to do it as a cashier. Within a week or two that job was over. I'm sure one of the supervisors was just frustrated, like why can't you get it? She can't do it. So some unrealistic jobs...Now she's working for a hotel, she's the housekeeper. It's the same job pretty well everyday, you clean the hotel rooms, and you need to do it to this standard, and they check the standards intermittently so you never know which rooms they will check. And that's the best way for Elizabeth, is to

know exactly what it should look like when it is done, so she is good at the job and is well paid.

However, success in employment was not experienced by several others in this study. Deidre explained that Dylan's jobs "don't last more than a month, which is going to be scary for him because to be able to succeed in life you have to work. Only working a month is not going to pay the bills." Lorraine felt that Larry needs "some place where he was being told what to do all the time." Gloria described her perception of what 12 year-old Gavin needs to be successful in employment:

> He can't pack groceries. What is light, and what's heavy? That's a judgment call. He can put things in a bag but you know that watermelon is going to go on top of the eggs every time. Well the eggs are heavy! (Laughs). No, they're fragile. He couldn't do janitorial work...He could do like assembly line work, same thing same way every time, no judgment. There is something out there for him. There will be. Maybe it will be paid employment or maybe it won't.

Taken advantage of

Related to challenges creating and maintaining friendships, children with FASD in this study were often "taken advantage of" by peers. Some parents explained that their children had no "true" friends, while other children became connected with negative peer relationships.

Jane described how Jeremy created friendships, "He started to steal money and buy friends. He would buy cigarettes for his friends and that's how he made friends." Ellen explained that Elizabeth was so "desperate for a friend she could be

that she would pretty well do anything." Deidre noted that Dylan's gift of generosity made him prone to being taken advantage of, "When he gets treats he shares with everybody, and a lot of kids take advantage of that. They know that Dylan is like that...That's a great gift he has, unfortunately it goes against him..." Gloria described Gavin's social immaturity at school:

> He loves people, but he's so naïve. We won't let him take valuable things to school, but he really wanted to take a basketball to school, and then it got 'lost', and then he got a book that was stolen. I think the other kids know that he is, you know. But he just loves everybody in his class. So as a boy he was being bullied, and the strategy is just to stay away from [the bully]. So if he's in line, you just wait for someone else to line up, don't stand beside him in line. And if he comes behind you leave the line and go to the back of the line. We tried to teach him these things, well this boy talked to him one day and was nice to him. Well he's my friend. Now he's the nice boy.

Gloria further described that, in social relationships, Gavin "has no insight."

Allison explained that Andrew is a "follower." Frances said that Fraser is "associated with a fairly negative peer group because they're the ones that accept him." Lorraine noted that 20 year-old Larry is "so easily led astray" by negative influences. Because several children in this study were prone to negative social relationships, many ended up getting in the wrong crowd.

In the wrong crowd

People with FASD are at much greater risk of getting into trouble with the law (Streissguth, 2001). Parents of adult children with FASD in the present study were

concerned about potential for criminal and gang involvement. Jane shares her story of rescuing Jeremy from "gang hits", where he was at-risk of being killed:

> He's been involved in gangs, we know that. But because he doesn't understand things the way other people do, they will give him drugs to sell, and he'll sell the drugs and then spend the money himself. So we've had several instances where there have been gang hits on him, so it's either we pay the debt and free him up, or we risk having him killed…I've been able to, through the police, make some contacts with some of the higher profile older gang members who maybe aren't necessarily involved in criminal activities anymore, but are still considered to be part of the gang, and suggest to them that Jeremy isn't a good risk. He has a history of basically stealing from the gang, so they might want to not consider him, and as far as I can tell that's having some effect…We had to get really creative to figure out how we were going to stop this cycle from happening because he just doesn't understand…and if we kept rescuing him there's no deterrent, and yet if we don't rescue him it likely will mean death, so I had to figure something out. I can't control him so I have to control the environment.

Creating a Bubble

By "controlling" Jeremy's environment, Jane was able to help prevent her son being seriously hurt or killed. Because of their children's risk of social problems and learning deficits, many parents needed to find ways to control their children's environments to keep them from harm.

In response to the death threats placed on her son, Jane has "infiltrated his life" to try to prevent his involvement with gangs. To prevent Dylan from "going down the wrong path", Deidre has "sheltered" him for most of his life. Frances tried to put "controls" on Fraser's life such as restricting activity with inappropriate friends. Jane described that controlling Jeremy's environment was necessary for promoting success, "I can't control what he does. I just have to figure out how to control the environment as much as possible to allow him the most success."

Getting Support

Parents reported barriers and successes in getting help from support networks, medical and mental health professionals, schools, government agencies, and community organizations. Bob expressed frustration with government and community agencies' "inability to provide respite help…you just can't get a break when you need it." Lorraine explained that "other people don't seem to understand" Larry's deficits, and noted that Larry's school could have been more accommodating. Deidre related that she "didn't have the families' support" because they did not believe Dylan had FASD. Frances felt that involvement with the medical system was detrimental to Fraser's mental health at present:

> Looking back, I really think that it would have been better if I had not gone through the mental health system…after two years of Risperdal he put on a ton of weight and he was very sedated…It had a lot of negative effects and it really didn't do anything positive for him. At best, the anti-psychotics helped him with his agitation, but it went way beyond agitation to the point where he was actually sedated. I can't get him back (to the doctor) now because of this

> experience and he says that he found it damaging going through the mental health system, because he always felt he had something wrong with him so he just saw that as a negative. Now he won't take medications. He won't go see a psychiatrist even though he has significant depressive symptoms. He's had psychotic breaks. But he has zero confidence in the mental health. So and he probably would benefit from some medications even if it's just antidepressants, anti-anxiety medications. He just won't go and I think it's because of his experience with the mental health system.

In contrast, Deidre indicated that she was "really lucky" that the school accommodated for Dylan. Christine explained that the hospital provided "a lot of really good ideas" for parenting Chad. Mark expressed gratitude toward workers from a community agency for comforting him when his children were diagnosed with FASD, and for teaching him to be "more patient" with his children. Ellen recognized that many children with FASD are not adequately accommodated in school. She described that successful school supports for Elizabeth may be in part due to Ellen's work in the disabilities field and her efforts in advocating for Elizabeth:

> She had great support through school, terrific support. Maybe that's [the school board], maybe it's what people thought I might know or who I might know in this kind of work, but she got terrific support. I felt kind of guilty because sometimes you see kids and they are struggling and they're not getting that support. Her siblings never got it either because nobody fought for them. I felt guilty that Elizabeth got more than anyone else, but I can't do anything about their kids.

FASD specific strategies provided by these personal and professional supports were beneficial for parents raising their children. Karen explained that using the strategies "help a lot" for preventing tantrums. Deidre is always seeking to update herself and "learn more about" FASD. Traditional behavioural management strategies tended to not be effective because, as Karen stated, these children "can't comprehend cause and effect and consequences." Some strategies shared by these parents include warnings for upcoming transitions (i.e. leaving the store), repeating instructions, structure and routine, using visuals to outline routines and instructions, and recognizing sensory processing issues such as sensitivity to light or clothing. Christine frequently provides feedback to Chad for his behaviour with thumbs up/thumbs down. In teaching Elizabeth about social interaction, Ellen likened communicating to a tennis match, "they say something, you say something." In addition, parents emphasized that in using these strategies, remaining patient is paramount because, as Christine observed, "I'm going to have to tell (him) twenty-five times. It's normal."

Some parents felt unsupported as they indicated they felt blamed for their children's behavioural challenges attributable to FASD. Frances explained that in her work in a mental health setting, she sees "a lot of blaming parents when the kids have very significant disorders." Christine had to use a harness for six year-old Chad because he would run away in stores, thus placing him in danger. Christine related that she obtained a doctor's note for the harness because "this lady said it was child abuse and threatened to call the police on me." One might wonder that, if this person saw FASD "in everyday life" (Gloria), if she would reserve judgment about whether

use of a harness constitutes "child abuse." Christine elaborates on how many people "don't understand" what it is like raising a child with FASD:

> It's a really hard thing to deal with people because they don't understand. Until you've actually had to raise a kid (with FASD) or look after a kid that has it, they don't get it and they can tell you they do but they don't get it. They had parenting groups at my daughter's school and they have all these solutions and life fixes. "Well try this because this works really well" and you just get to the point you're like, whatever. They hand you all these life fixes and all this information and it's like okay, you don't get it. It's not going to work. They say "Well you just didn't try hard enough." No it's not going to work, okay? He's not going to do it because it doesn't work like that. Then it's usually, "well you didn't try hard enough" or "if you would've done this with him", and "well he gets away with too many things." Well it's not that he gets away with it, he doesn't know better. He doesn't understand. You can't make him get what he isn't going to get. People have a hard time with that…Parents look at you like you're a freak because you're really strict with him. They look at you like you're a mean ass and it's like, no, you don't get it. If I tell him nicely in twenty words, he's lost.

Re-defining success

Several parents described a transformation in their expectations of their children as they have come to learn about the cognitive, learning, and behavioural challenges associated with FASD. Re-defining success involves setting more realistic expectations for their children in light of their deficits.

Karen feels that she used to "blow up at the littlest things." Christine has developed "a lot more compassion" as she has come to understand Chad. Frances explained that "you have to really accept a lot of limitations and you just have to learn some things are not in their control and they are not going to get better." Ellen noted that she has a "different yardstick" for Elizabeth, and that her "big goal for the next five years is not to have Elizabeth and a baby moving back in. That would be success." Bob explained the need to accept his children's limitations:

> You always want them to be better than they are but you have to realize all the love and nurturing in the world is not going to get them from point A to point B. You have to come to terms with their limitations. Build them up where you can and leave the rest alone. Don't keep fighting it.

Christine described that her long-term expectations for Chad seem pessimistic but are sensible:

> My whole thing with Chad, my whole goal in his life is to keep him out of jail. That's my goal. If I can keep him out of jail, I've succeeded. That's all I want... that's pretty sad but that's a good hope for him.

The lifelong parent

The lifelong parent represents parents' perceptions of lifelong challenges associated with their children's disabilities. It is suggested by them that their children will be dependent on some sort of support throughout their lives, and that their role as caregiver does not end when their children turn 18 years old. Interestingly, Jane's 18 year-old son Jeremy and Lorraine's 20 year-old son Larry telephoned their mothers during the interviews because they were in need of assistance.

When Mark's daughter was diagnosed with FASD, he felt that she would "probably stay with [him] forever." Allison laments that she "won't be around forever" to support her son. Ellen feels that it is unfair that her need to be vigilant in looking after her 21 year-old daughter "will never end." Lorraine explained the "lifetime commitment" of raising a child with FASD:

> There's no saying you're 18 now they can go, or they can be home and you don't have to worry about them. You always have to worry about them, and it's hard because you never know what they're going to do. They could end up with a gang, they could get hurt easily drinking and being in a crowd. They're so easily led astray…Yeah, it's a lifetime of worrying about them.

Gloria expects that Gavin will always need some kind of assistance:

> I expect, he'll always need some kind of supervision. I don't think he could do banking, work out his schedule, transportation, he cant remember to take medication. If I wasn't there to say okay, this is what you are going to have for lunch, he wouldn't eat, or he would just eat chips, and I expect that he will always be that way. So he will need some kind of minimal assistance in a group home, or some kind of support.

Gifts

Although participants primarily emphasized their challenges raising children with FASD, many parents also discussed their children's gifts. Mary and Becky are gifted artistically. Jeremy is "an amazing musician, a gifted athlete, a loyal friend." Gavin is "warm and friendly. He always tries his best, and he wants to make others happy." Makayla is "a little ham." Andrew can be "a real kind and sweet person",

and Dylan is "compassionate and forgiving." Jane shared an experience that helped her understand that Jeremy "sees the best in everybody":

> When he was a young kid there was a neighbor girl that moved to town, and she had a bit of a crush on Jeremy. She was in his classroom, so she was drawing pictures and stuff. I can remember teasing him and saying, 'oh, is she cute?' He said to me, 'mom, everybody is beautiful. You just have to know what to look for.' I thought, wow. Talk about a profound statement coming from this kid.

Karen explained that although the effects of prenatal alcohol exposure have negatively impacted Kevin's behavior, having FAS is part of "who he is":

> I don't know how to explain it without sounding really horrible. In a way, Kevin wouldn't be who he is without his FAS. And I guess that part of that is his impulsivity…I think in a way that his traits in FAS make him who he is, and I love who he is. I don't want to say I'm glad he's affected or that I wouldn't want him not to be affected, but I like the spunk, and I like everything about him. It's not that I love that my son has FAS, but all the personality traits and everything that comes along with it is such a blessing, a gift for him.

Chapter V

Reflections

The themes derived from the interviews are largely in line with research on parenting children with FASD. In feeling that "something's not right" with their children, parents in this study related similar feelings to those parents interviewed by Granitsas (2004), who explained that they had been given incomplete information, if any, about their children's diagnoses. In addition, Frankel, Frankel, & Opie (2007) also found that the adoptive parents in their study were not fully informed of the possible consequences of prenatal alcohol exposure, despite the knowledge or suspicion that their children were exposed to alcohol prenatally. Informing adoptive/foster parents of the possibility or likelihood of prenatal alcohol exposure does little to empower them if information on the effects of FASD, appropriate strategies, and access to additional supports are not also provided.

In the interviews, the topic of abortion of a fetus prenatally exposed to alcohol was not brought up or discussed by any of the participants. This seems consistent with the interviews in general – although parents described many challenges with their children with FASD, they note that they felt unified with their children. This is most apparent in Karen's comment on how "Kevin wouldn't be who he is without his FAS", and that although she would never hope for deficits for him, she cares for him as he is now. With this context, it would be difficult to conceive Karen talking about her life if Kevin was not born, but terminated during his mother's pregnancy. Although the topic of abortion did not arise in this study, it might be something that other biological parents have participated in. Research could be conducted in this

area to determine whether some biological mothers who drank during pregnancy sought abortion, and how that may have impacted their lives.

Like participants in other studies (i.e. Frankel, Frankel, & Opie, 2007), parents were challenged by not knowing where to seek out information about FASD. In addition, parents expressed frustration as they dealt with educational and health professionals who lacked knowledge of the effects of prenatal alcohol. Nevin et al. (2002) surveyed 75 physicians in Toronto, Ontario, half of whom had very little confidence in their ability to diagnose FAS, and none of whom were aware of the accepted screening method for alcohol use in pregnancy. In many areas that seem to experience higher prevalence of FASD, such as rural areas of Northern Canada, clinicians have few professional resources available to them (Hay, 1999). A general lack of awareness of FASD is also found in nursing (Hess & Kanner, 1998). It seems that there are few practitioners in health, education, social services, and justice systems that have a working knowledge of the effects of FASD (Brown, 2004). In addition, many parents feel that their knowledge of FASD is not regarded or utilized by professionals (Brown & Bednar, 2004).

Receiving a diagnosis of FASD early in a child's life may be a crucial step to preventing future social problems (Streissguth et al., 2004). It was apparent in this study that receiving a diagnosis elicited strong emotional reactions from parents, including grief over dashed hopes for their children, guilt over alcohol consumption or prior parenting practices, relief for the explanation and normalization of their children's challenges, and validation that children's troubles were not caused by bad parenting. In Armstrong (2003) physicians shared that an appropriate FASD

diagnosis can provide relief and explanation to parents living with the disorder. Although there is research regarding the importance of obtaining a diagnosis for families who have children with developmental disabilities (Carmichael et al., 1999; Watson, 2007), little research was found focusing on the experiences of parents receiving their children's diagnoses of an FASD. One exception is Ryan & Ferguson's (2006) in-depth qualitative study of 5 families of children with FAS, where parents expressed, "If I knew then what I know now" (p. 372), their parenting strategies and expectations of their children would have been different. Reactions to a diagnosis of FASD may differ from developmental disabilities because the deficits of FASD are different, and blame can be allocated to birth mothers. Because a diagnosis has the potential to alleviate family tensions (Armstrong, 2003), research evaluating parents' experiences receiving diagnoses of FASD for their children is needed.

"The FAS label has the power to both apportion blame and erase it" (Armstrong, 2003, p. 128). Although attitudes toward birth mothers were not anticipated at the commencement of the study, it does provide important insight into the feelings and perceptions of adoptive/foster parents of children with FASD. Like parents in this study, participants in Gardner's study of foster parents (2000) expressed feelings of anger and frustration toward birth mothers for drinking during pregnancy. The result of such intense feelings may negatively impact family functioning (Jones, 1999). Practitioners consulting with adoptive and foster parents of children with FASD should be aware that parents may hold harsh feelings toward

birth parents. Helping parents cope with anger and resentment may be an important step in promoting healthy family functioning and society.

Clinicians are encouraged to adopt a respectful, open, "non-blaming and non-shaming" attitude toward birth parents during the FASD diagnostic process (Hay, 1999, p. 37). Some physicians interviewed by Armstrong (2003) felt angry toward birth mothers, whereas others felt saddened, compassionate, and forgiving. Some of these doctors recognized the complexity of social problems associated with birth mothers' drinking. "Many doctors, in fact, perceived FAS as enmeshed in a broader web of social dysfunction shadowing a family's life" (p. 122). This social dysfunction for many birth mothers is apparent. Astley et al. (2000) profiled eighty birth mothers of children with FAS. The researchers determined that these women demonstrated "a harsh psychosocial profile" (p. 515); 93% of women experienced more than one mental disorder, 95% had a history of physical or sexual abuse, and 86% had a history of illicit drug use. In addition, there were on average 3.3 unplanned pregnancies per mother (sd = 2.0). In this light, FASD is only part of a considerable social problem. Prevention of FASD extends beyond educating would-be parents about the impacts of prenatal alcohol exposure; addressing the broader issues of psychosocial dysfunction and family planning is needed. This can be done by providing on-going support for mothers who have had children with FASD through support groups and other social programs. In addition, providing education and support to would-be mothers at-risk of drinking alcohol during pregnancy may help to prevent FASD.

Jane described that Jeremy's violence and aggression created a home environment that was "like living in a war zone." Violence, antisocial behaviour, and conduct-related disorders are associated with prenatal alcohol exposure (Schonfield, Mattson, & Riley, 2005). Living with an FASD child with externalizing behaviour problems, such as hyperactivity, aggression, and destructiveness, can be stressful (Paley et al., 2006) and discouraging (Gardner, 2000) for parents. Coping with these externalizing problems can be demanding on parents and interfere with self-care (Brown & Bednar, 2004), which can then spiral into further stress (Paley et al., 2006). Parents need to be encouraged to adopt self-care practices, and empowered to do so through community support and respite services.

Greater understanding of children born with FASD is needed to promote long-term success for them (Streissguth et al., 2004). The largest central theme in this study, Understanding my Child, reflects parents' learning about their children's challenges associated with FASD. This theme title is more accurate than Understanding FASD, because each child in the study presented with characteristics of FASD in a unique way. Some demonstrated hyperactive or aggressive behaviour, whereas others showed profound learning challenges. Although a behavioural phenotype is needed (Kodituwakku, 2007), children with FASD do not fit strictly in a rigid behavioural description (Frankel, Frankel, & Opie, 2007). The frequency, intensity, and timing of alcohol consumption during pregnancy can lead to a variety of deficits of different magnitudes (Pei & Rinaldi 2004). For this reason, an individualized approach to parenting based on the child's strengths will help promote future success (Brown, 2004; Frankel, Frankel, & Opie).

Children with FASD can experience significant cognitive, memory, and executive difficulties (Mattson, Schonfield, & Riley, 2001) that can impact their school, home, and social functioning. Because of problems with short-term memory, organization, learning, retention, regulation, and social awareness, these cognitive concerns may permeate most or all of the secondary challenges of FASD described by Streissguth et al. (2004). Coping with learning and memory challenges was frustrating and disheartening for parents in this study, and many felt guilty for assuming that their children were "forgetting" purposefully or maliciously. Children forgetting skills and routines that were thought to be crystallized was a difficult concept for parents to fathom, and seems to have been unexplored in the research literature. During a follow-up visit, Karen, who works as a FASD support person, explained that she still has difficulty understanding how Kevin can forget skills that he would practice routinely. She shared an experience that occurred after her interview where Kevin seemed confused and requested help with his clothes, even though he had been dressing himself independently for 2 years. Her first reaction was to suggest to Kevin that he knew how to do it, but after some reflection she realized that he really did forget how to dress himself. In the past, she would have reacted with impatience and expected Kevin to dress himself. With her knowledge of FASD, she instead helped him with his clothes, in the hope that he would remember how to dress himself the following day. Because of the stresses and confusions it can cause for children and families, this "forgetting" of apparently crystallized skills requires further investigation.

Caregivers' assumptions of what their children should know and remember may be confounded by the invisibility of FASD in many cases. Chudley et al. (2005) suggested that the facial dysmorphology associated with FAS is relatively unimportant when compared with the central nervous system dysfunction caused by prenatal alcohol. Although facial dysmorphology is a diagnostic characteristic of FAS, deficits in intelligence (Rasmussen, Horne, & Witol, 2006) and executive functioning (Rasmussen, 2005) are also demonstrated in patients with prenatal alcohol exposure absent of facial characteristics. In fact, absence of facial dysmorphology has been shown to be associated with unfavourable life outcomes. Adolescents and adults with FAE are significantly more likely to have disrupted school experience, trouble with the law, and alcohol/drug problems than those with FAS (Streissguth et al., 2004).

The invisibility of FASD can be a barrier to accessing appropriate interventions and supports (Frankel, Frankel, & Opie, 2007). Based on their sample of 415 patients with FAS/FAE, Streissguth et al. (2004) found that only 13% of them would qualify for disability service based on the typical cutoff of IQ<70, despite marked deficits in adaptive behaviour. As a result, many parents are required to put effort in lobbying and advocating to access needed supports, (Brown, 2004), which time and energy could be better utilized focussing on their children.

Ellen described that the invisibility of Elizabeth's disability has gotten her in trouble at work in the past. Elizabeth's past employers assumed that she was able to follow through with instructions because she "did a lot of masking" by communicating that she understood her tasks when she did not. Based on her

apparent challenges in understanding how to engage appropriately in social interaction, it seems likely that Elizabeth said that she understood her tasks because she felt that was her role in her social "tennis match", rather than intentional deceit.. Because of the invisibility of FASD, school personnel and employers may have unrealistic expectations of their students/employees. These unrealistic perceptions, combined with difficulties with learning and memory (Mattson, Schonfield, & Riley, 2001), organization and planning, (Rasmussen, 2005), and mental health concerns such as depression (Famy, Streissguth, & Unis, 1998), may create barriers to success for children and adolescents in school and for adults in their employment. Yet, as expectations are re-defined, as children's strengths are recognized, and as stable, supportive homes are provided, children with FASD can find success in life. Elizabeth exceeded her mother's expectations as she maintains paid employment, lives out of home, and is involved in a stable relationship with her boyfriend.

Elizabeth appeared to experience the greatest degree of independence among the four adult children in this study, but she was also the only female of the four. In this light, the gender of the FASD child may be a factor in determining long-term social outcomes, consistent with research by Streissguth et al. (2004).

Patients with FASD also show lags in social development. Thomas et al. (1998) found that children with FAS demonstrated weak interpersonal skills even with differences in intelligence factored out. This suggests that lags in social development for children with FAS are attributable only partially to intelligence, if at all, and that other factors seem to contribute to lower social ability. Like the participants in this study, parents in Gardner (2000) expressed that they were worried

about their children because they were "naïve" and would be "taken advantage of" (p. 256). As children grow into adolescence, their social lives become increasingly complex, and the gap in social ability widens between adolescents with FASD and their peers (Kodituwakku, 2007). This seems to relate to parents' responses in this study, in that their children were "so easily manipulated" and had no social "insight". Their lags in social development, perhaps in conjunction with other cognitive abilities and mental health concerns, may put adolescents and adults with FASD at greater risk of gang involvement.

Parents' experiencing their children with FASD being involved with gangs and getting into trouble with the law is not surprising (Streissguth et al., 2004). Adolescents and adults with FASD are more likely to engage in anti-social behaviour (Schonfield, Mattson, & Riley, 2005) and are over-represented in the criminal justice system (Chudley, 2007; Fast, Conry, & Loock, 1999). Their susceptibility for conduct-related problems and tendency to be easily manipulated may put them at increased risk for gang involvement. Although gang involvement is a very serious concern (according to Jane, possibly deadly), parents' stories of their children's gang involvement have apparently not been discussed in research literature. Research on parents' experiences with FASD (notably Gardner, 2000; and Granitsas, 2004) have only explored parenting of minor children who still live at home. As this study noted, however, parenting children with FASD is a "lifelong commitment" (Lorraine) that does not expire when children move out of home. Being "in the wrong crowd" may be a significant concern for adolescents and adults with FASD, and more research in

this area may help inform parents and professionals how to cope with, and how to prevent, involvement in gangs.

According to Streissguth et al. (2004), children with FASD need to be "protect(ed) from the hazardous straits into which they are born" (p. 236). Because of their cognitive disabilities, patients with FASD can be vulnerable to being manipulated by others. Parents in this study encountered the same need to protect their children from untoward peer associations and from being "taken advantage of". In "Creating a bubble" of protection, parents seemed to be cognizant of their children's "hazardous straits", and intervened in the hopes of promoting success for them. For Jane, "Creating a bubble", worked to save Jeremy's life without him knowing.

Practitioners may assist parents in protecting their children from social threats by relating the story of Pinocchio (Disney, 1940). Jiminy Cricket acted as Pinocchio's conscience to guide him in his endeavours, whereas Gepetto was Pinocchio's caregiver. Pinocchio had the help of an external conscience in Jiminy, yet ignored his advice at times which got him into trouble (such as when the bully Lampwick stole his candy). At other times, Pinocchio hearkened to Jiminy's exhortations, and was eventually rewarded as he turned into a real boy. In sharing this story, parents may be made aware that they can best help their children, not only as a caregiver (Gepetto), but also as an external "conscience" (Jiminy).

Because of the extra demands of parenting children with FASD, parents need support in promoting success for their children. Important support needs for parents include a personal support network (Brown & Bednar, 2004), professionals who are

empathetic and knowledgeable of FASD, and a good working relationship with the child's school (Brown, 2004). However, parents in many studies expressed frustration in dealing with professionals who lack knowledge (Frankel, Frankel, & Opie, 2007) and empathy, which can contribute to parental stress (Hess & Kanner, 1998). Many medical (Nevin et al., 2002) and educational (Ryan & Ferguson, 2006) professionals themselves express that they lack sufficient knowledge of FASD despite working with this population. Despite this lack of knowledge on the part of many professionals, parents' expertises on the disorder, and insights on what strategies are most useful to them, are often dismissed (Brown & Bednar).

Parents in this study seemed to internalize the importance of creating realistic expectations for their children. Changing expectations may be an important coping strategy for parents (Gardner, 2000), and may be a characteristic of successful families according to Frankel, Frankel, & Opie (2007). These researchers also emphasize the importance of "under-reacting" when children with FASD misbehave because behaviour that seems malicious may be due to learning, memory, or processing deficits. Information about realistic expectations should be frankly shared with parents, and more research about parental expectations is needed.

The consequences of prenatal alcohol exposure "appear to persist throughout life and to require lifelong supports" (Ryan & Ferguson, 2006, p. 364). This can be troubling for parents, who may become lifelong caregivers to some extent for their children. Although some of their children may achieve a degree of independence (i.e. Elizabeth in this study), others will likely require support to some degree. Because of the invisibility of disability and because average IQs for FASD populations exceed

typical cut-offs for adult support, much of this burden will likely fall on parents. Fears for not knowing their children's future were expressed by parents in articles by Gardner (2000) and Granitsas (2004), but literature examining actual experiences of parents of adult children with FASD was not located. Because of the lifelong need for support and advocacy, further research is needed in this area.

While recognizing the deficits characteristic of FASD, it is also important to recognize these children's strengths, skills, and gifts. Each child is more than a case of FASD (Streissguth, 1997). Parents in Granitsas' (2004) study explained that they felt pride in their children, and recognized their children's abilities, which for many was in music. Parents in this study also recognized their children's gifts amidst a myriad of social, cognitive, and behavioural deficits. In working with families, clinicians and educators should recognize children's gifts to create strength-based intervention programs (Brown, 2004) and to work empathically with parents (Hay, 1999).

Several themes in this study seem consistent with existing qualitative research on parenting children with FASD. In this light, it seems appropriate to expand research on this topic to obtain more generalizeable findings. For example, parents' experiences with "not knowing" about their children's deficits before adoption can be explored using larger samples of participants and quantitative methodologies. Findings from exploratory qualitative studies on parenting children with FASD to date have laid the groundwork for further research into the lives of parents, and obtaining additional generalizeable findings may lead to positive changes in the prevention of FASD and how families' access support.

As I interpreted the interviews with parents in this study, I was struck by parents' patience in coping with what could be described as hellish circumstances, and with their willingness to sacrifice their own desires, wants, and needs for their children. In hearing their stories, experiences, frustrations, and joys, I felt that they represented the embodiment of altruism. Many of their stories will touch hearts and, if listened to, should be a catalyst for change for improving how society views and supports parents and children with FASD.

A phrase or two

At the conclusion of interviews, parents were asked to sum up their experience in a phrase or two. Although the parents expressed significant challenges, they also experienced personal growth and unity with their children.

Karen emphasized that raising Kevin was "life altering", and that it has taught her a lot "about being patient." Frances explained that it was "an incredibly stressful" experience, because "its very hard to make a family seem like a family". Bob said that he wished "our society could do something to address the larger issue" of some birth parents repeatedly having children born with FASD. Lorraine emphasized that being a parent of an FASD child is "a lifetime commitment." Jane explained that raising Jeremy was, "an extraordinary learning experience. I don't know (cries). I get very emotional when I talk about him. I think Jeremy has been a huge gift in my life." Deidre sums up her experience in a few pithy statements:

> It's been frustrating, overwhelming, never a dull moment, new experiences all the time, makes me a stronger parent, stronger person, but yet I'm very weak in a lot of ways still. I can laugh today where I cried yesterday at the

behaviors. But he's my world and he's my joy, and I wouldn't change it for the world.

Mark expressed satisfaction for his "journey" raising his two biological children with FASD:

> I think I've been blessed that I have these two girls in my life; they are very special in their own way. I don't know what I would do without them if they weren't in my life. It was a long journey! But it was worth it...I could be helping them the rest of their lives...They probably remember all the things I helped them on and what I did for them. I think they will appreciate all things I did. I give myself a pat on the back!

Certainly, many parents of children with FASD deserve "a pat on the back". By providing these families with the supports recommended in this paper, family members, teachers, professionals, support personnel, and the community can help promote successful family functioning for families raising children with FASD, which can help promote lifelong successes for those living with the disorder.

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